

Family Councils



How to build & maintain a strong & effective one

**To support residents of
long-term care homes**



Introduction

At some point in our lives, many of us will need to help a family member or loved one decide about moving to a long-term care home. This may involve visiting various homes, researching state survey results, talking to others who have already taken this step, and other tasks to ensure a good choice is made. Once a decision is made for your loved one to move to a long-term care home, what happens?

- Does your responsibility end?
- Will you still need to be involved with his or her care?
- Who will answer questions and help resolve concerns?
- How will you know he or she is happy and well cared for?
- Is the home supposed to do everything for your loved one?

Many residents of long-term care homes are unable to ensure their own quality of care and dignity of life without assistance from someone. The individual should always be allowed to make their own decisions and choices whenever possible, but family members and friends often need to stay involved in their loved one's care and be available to speak for them when necessary.

A good way to continue helping your loved one is by participating in the home's **Family Council**. If the home does not have a family council, **consider starting one!**

SPECIAL NOTE

C**ulture Change** is the common name given to the national movement for transforming long-term care services to be more person-centered than institutional, while allowing residents to make personal choices in meaningful ways at every level of daily life. Residents and caregivers alike are encouraged to think of a 'facility' as the individual's choice of a home that provides needed services, rather than an institution where the person is placed to receive care.

In support of this movement and an individual's right to make personal choices, this booklet uses the term "long-term care home," or simply "home," instead of institutional terms such as nursing home or long-term care facility.

What is a Family Council?

A family council is an organized, independent and self-led group of family and friends of persons living in a long-term care home. The family council meets regularly to discuss shared concerns about the quality of life and quality of care of the residents in their home, and find answers to shared problems. All family councils promote communication, action, support and education. The activities of the council depend upon the needs of the residents and the choices made by council members.

Similar to parents' associations that work with schools, family councils provide a way for family members to actively participate in improving the quality of life and quality of care for all residents of the long-term care home. Working together, the family council can help the home be the best it can be in providing quality care and supporting individual dignity of life.

Why have a Family Council?

Simply put, family councils are THE BEST -

- The best prevention against abuse and neglect;
- The best way to persuade a long-term care home of the need for a change in culture;
- The best way to involve the community in the life of the home;
- The best way to show ongoing appreciation for staff; and
- The best way to address systemic issues regarding changes in laws, regulations and policies that affect residents in long-term care homes across the state.

What one person cannot accomplish alone can often be done with help from others. Hard as you try, you can't see everything. Smart as you may be, you can't know everything. When you act alone, it's easier to have your concerns dismissed – when several individuals work together, there is strength in numbers.

Other residents' family and friends can be there when you are not; they may see what you do not; and they may have ideas that haven't yet occurred to you.

Together, your voices have strength and authority.

How to Build an Effective Family Council

1) Hold an Informational Meeting

- Talk with the home's staff about your plan and request their help to organize the meeting, if needed.
- Invite all the family members and friends of residents to attend.
- Designate one person to take meeting minutes, including names of those who attend.
- Designate a person to explain what a family council is, what it does, and why it is important to have one. You may request help from your regional or state Ombudsman office to explain this topic.
- Provide sample bylaws and mission statements to help guide discussion and decide on leadership.
- Ask everyone to provide their contact information, including mailing address, phone number(s), email address, and preferred method of communication.
- Discuss when, where, and how often the group should meet.
- Ask for volunteers to help organize the next meeting.
- Ask the home to designate a staff liaison for the council.

2) Follow-up After the Meeting

- Post meeting minutes in the home and give a copy to the designated staff liaison.
- Post information about the first 'official' council meeting.
- Contact family members and friends about the meeting and ask the home to include a notice in their next newsletter or other mailing.
- Plan the meeting and complete an agenda. Set an end time and stick to it.
- Ask every potential council member to come to the meeting with a list of issues they want to discuss and at least one job they are willing to do to support the council's success.

3) **Hold the First Family Council Meeting**

- The whole group should discuss and adopt your mission statement and bylaws, keeping them simple and easy to follow.
- Some councils have membership applications and collect minimal dues to support projects. Think about whether or not you want to do this.
- Elect officers as determined in the bylaws and turn the meeting over to them.
- Every member should be willing to devote some time to the group. Simple tasks that support the officers' leadership are often very helpful – posting notices, making phone calls, etc.
- Discuss issues members want the council to work on and form an Action Plan to help keep them on track.
- Choose the next meeting time and place, if necessary.

NOTE: Any facility staff attending this meeting should excuse themselves if the group begins discussion of issues.

4) **Keep the Council Moving!**

- Don't miss a chance to publicize meetings and recruit members.
- Invite the family members and friends of new residents to attend meetings and participate in activities.

Never Forget Your Primary Goal — to Make Life Better for all Residents!

What the Home is Required to do

The 1987 Nursing Home Reform Act guarantees the families of long-term care home's residents several important rights. These rights were established to support the residents' quality of life and improve services and conditions for persons living in a Medicare or Medicaid certified facility.

One of those rights guarantees that family and friends may form and hold regular meetings of a **family council**. Both federal and state laws and regulations also say:

- The council can meet wherever it chooses. If the council wants to meet at the home, it shall be given access to a private meeting room during mutually agreed upon hours.
- Staff or visitors may attend council meetings **only** when invited by the group.
- The home shall provide a designated staff person to assist the council and answer written requests that result from family council meetings.
- The home must listen to the views and act upon the grievances and recommendations of residents and families.
- The home may not prevent the formation of a family council when requested by the family and friends of residents.

The Council is Formed — Now What?

A functional family council must have organization, active membership, and the ability to take action. The council is most likely to succeed when it has good communication with staff. The groups may not always agree, but the ability to discuss an issue is essential to solving it.

You must be organized. People without direction, leadership, or structure are not as effective and often find it difficult to get others to participate with them.

You must have active members. Current members must be active and new members must be recruited to keep the group alive and functioning. The more family members involved, the greater number of voices that will be heard and the stronger the group will be.

The family council must act. The council might hold educational meetings for members or staff, sponsor resident activities, or ask the home to address specific quality-of-care issues. Include fun events or speakers in your activities to help keep things fresh and supportive for everyone.

Organization

Family council members donate personal time to improve the quality of life of somebody they love. It is important to use their time effectively and efficiently. To stay organized and on-track, the council needs:

- A mission statement that describes the group and its purpose.
- Bylaws that set the rules for meetings and how the group will operate.
- An agenda that describes what is supposed to happen at each meeting. Sticking to the agenda helps members stay focused on their purpose. The council succeeds only when members work together to decide what they want and how to get it.
- Minutes taken by a member at every meeting so that all members know what happened at every meeting and what action was taken by the council.
- A plan to share information – a phone tree, emails, a bulletin board in the home. Be sure the council's activities are shared with everyone.
- An Action Plan form to express concerns to the home and require a written response.

Membership

To keep current members (AND get new ones) the family council should:

- Post family council meeting information where all visitors can read it. Consider using a bulletin board or table in the home to post meeting notices, minutes, contact information, activities, etc.
- Ask the home to reserve a spot for council updates in their newsletter or other mailings.
- Educate staff about the family council so they can refer new family members.
- Consider using a suggestion box for meeting topics or issues for discussion.
- Personally invite new family members to attend meetings and activities.
- Publicize meetings and activities in local newspapers, church bulletins, and other community resources.
- Ask the home to include family council information in their admissions packet.
- Sponsor activities for all family members and residents.
- Keep council meetings interesting, respectful and meaningful to all members.

Even when working on serious issues, it's important to keep a sense of humor. Build a cooperative spirit within the council and make time for fun activities.

Remember — People Often Volunteer When Someone ASKS Them to!

Planning and Taking Action

Think of your family council as a business – not a club or social group. You must be self-determining and self-organized in order to be effective. Think about short-term versus long-term activities. Some activities can be achieved rather quickly, such as an educational or staff appreciation event. Long-term activities might include staffing or other care issues. Try to achieve a good balance of both types to keep members positive and willing to persevere in resolving more difficult issues.

To help the council decide what to do, and how to do it, consider the following:

- Discuss concerns that affect many residents, along with their thoughts on why it is happening.
- Gather information: what needs to be done, who will be involved, and how soon they can start.
- Discuss possible solutions and how the family council can support resolution.
- Consider ways to document the existence of the problem.
- Formally present your concerns and proposed solutions to the administrator and appropriate staff by using the council's Action Plan form.
- Allow sufficient time for the home to respond to your concern and act on it.
 - Discuss the home's response and let them know if it is satisfactory.
 - If the response is not sufficient, consider discussing the issue with state or regional Ombudsman staff for additional guidance.
 - File another written request for action, if necessary.
- Once an issue is resolved, let residents, staff and family members know what was done!
 - Post successful outcomes on the bulletin boards, meeting minutes, newsletters, etc.
 - Be sure to show appreciation for the home's responsiveness to your concerns.

The family council takes all concerns seriously, but will generally focus on those that affect many residents. However, the council should help teach and empower families to advocate for their loved ones. Families should learn how to:

- Keep a log with the date, time, place, staff members and residents involved in any complaint.

- Take their concerns to the administrator or other appropriate staff, in writing.
- Raise any concerns when they occur instead of waiting for the council meeting.
- Attend and participate in care plan conferences for their loved one.
- KNOW the residents' rights.
- Know how to get help from the Ombudsman program.
- Learn about how other homes have improved care as a result of family council activities.

Keys to Family Council Success

Keep the following points in mind at all times to help ensure an effective and highly functional council:

- Meet with the administrator;
- Involve staff and residents;
- Keep lines of communication open;
- Post bylaws and mission statement;
- Post meeting notices and meeting minutes;
- Recruit, recruit, recruit;
- Stick to the agenda;
- Do your homework;
- Pick your battles;
- Put it in writing;
- Support good leadership;
- Every member needs a job;
- Communicate with ALL families;
- Be respectful of everyone's point of view; and
- Be aware of and celebrate the various cultures of residents and staff.

Troubleshooting

Despite everyone's best efforts, there may be roadblocks to overcome as you develop and maintain your council. The following information is provided to help members deal with obstacles that may come up.

- **Family members don't have time –**

- Begin and end meetings on time. When meetings are purposeful and effective, family members will be more likely to attend.
- Share leadership responsibilities and delegate small tasks to members so the time commitment is smaller.
- Use your agenda to keep meetings focused and on track.
- Schedule meetings at times that are most convenient for family members.

- **Family members aren't interested –**

- Get to know the other residents' family members. Most people will respond to a personal invitation from someone they know instead of a letter or flyer.
- Explain how the family council can help improve residents' lives.
- Be positive about the council and explain how useful it can be for advocacy, information sharing and support. Every long-term care home has room for improvement and new ideas.

- **Family members fear retaliation –**

- Explain that issues are presented to the administration as a group, not as individual concerns.
- Consider holding meetings outside the home if family members are concerned about being seen at the meetings.
- Let them know that other council members will provide support and encouragement.

- **Council members get discouraged easily –**

- Make sure council goals reflect common concerns and interests.
- Balance short-term and long-term goals so members can see progress.
- Meet regularly to make sure members understand the issues and are updated on their progress.
- Use other resources when stuck on a particular issue, including other family councils.
- Publicize council successes, no matter how small.

- **Council experiences resistance from the home –**

- Council leaders should meet with the home's management to discuss the council's purpose in a positive way.
- Communicate regularly and respond tactfully to concerns the home may have.
- Discuss and come to agreement with staff about how specific concerns can be resolved.
- Follow up on conversations with written communication to prevent misunderstandings.
- Know the rights guaranteed to family councils by federal regulations.
- Seek guidance from the Ombudsman program.

- **Council has difficulty getting names of other family members–**

- Complete a sign-in sheet at each meeting to gather contact information.
- Ask the home to provide space for council information.
- Set up a system to have council members greet new families and invite them to meetings.

- **Family members need information and education –**

- Arrange for speakers on topics of interest to attend council meetings.
- Contact the Ombudsman program.
- Use community and online resources included in this document.